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African Americans

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13. ABSTRACT (Maximum 200 Words) The purpose of this project is to develop methods to encourage earlier detection of breast cancer in rural African Americans. Our focus is on cultural and psychosocial beliefs that contribute to patient delay in seeking treatment for the symptoms of breast cancer. For the intervention phase, educational programs featuring a documentary video, public service announcements, and culturally sensitive brochures have been presented to over 2100 people in Pitt County. The final phase of the project involved post intervention surveys of women in both Pitt and Wilson Counties. Over 1400 surveys were completed and data analysis is currently underway.				
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Introduction:

The goal of this project is to develop methods to encourage earlier detection of breast cancer in rural African Americans. Our previous research has indicated two reasons for late stage breast cancer presentation in this population: (1) lack of breast screening including clinical breast exam and mammography, and (2) patient delay due to cultural and psychosocial beliefs.

Six attitudes or beliefs about cancer have been previously identified which are widely held in North Carolina and which correlate strongly with late stage presentation of breast cancer. These beliefs are: (1) on over-reliance on God to cure cancer without medical intervention, (2) reluctance for a woman to discuss a potential cancer with her husband or male partner because he would not be supportive, (3) a general fatalism that active medical intervention would not make a difference, (4) a specific belief that cutting into a cancer or exposing it to air will make it spread faster, (5) lack of knowledge that a breast lump can be serious even if it does not hurt, and (6) belief in alternative treatments and lack of confidence in surgery as a specific therapeutic modality for breast problems.

The current research seeks to ascertain when these beliefs are formed and test whether they can be modified. Through an extensive education intervention, we will determine if changing these beliefs increases rates of screening behavior and decreases delay in seeking medical care for breast symptoms.

The experimental design involves community-wide, in depth surveys of women ages 19 and over in two similar counties, Pitt and Wilson. These interviews are being conducted before and after the educational intervention which will be presented only in the experimental county, Pitt County.

Body:

This report is organized by tasks to have been completed during the current reporting period, months 43-60, as outlined in the approved revision of the Statement of Work. The original Statement of Work (letter D. of the original grant proposal) was modified for a one-year, non-funded extension due to delays caused by Hurricane Floyd and its subsequent flooding and relocations. In addition, we have requested a three-month, non-funded extension for Task 6, "analyze results and report findings," due to problems involving the hardware and software used to scan the completed interviews. The revised schedule involved delaying Task 4, "conduct intervention," to months 37-47 and Task 5, "conduct post-intervention survey," to months 43-60. The recently requested time period would delay Task 6 to months 61-63. The balance of this report covers the work accomplished relating to Tasks 4 and 5 as well as the beginning of Task 6.

Task 4: Conduct Intervention, Months 37-47

c. Implementation of Intervention

c. 1. educational programs for churches, civic groups, and work sites

During this period, we have continued to use our lay speaker's bureau to present educational programs, using our materials and video, to reach out to the community. All the interventions were directed toward Pitt County. From October 2000 to September 2001 we have conducted 14 programs attended by 439 people. Of these attendees, 193 were white and 246 were African American.

The evaluation reports continued to be very positive, especially regarding the video featuring six patients from eastern NC undergoing diagnosis and treatment for breast cancer. The effectiveness of these programs will be assessed in the post-intervention survey analysis.

c. 2. radio advertising campaign

As a continuation of **Task 3**, the public service announcements we developed were broadcast on local radio stations. We selected three stations targeting women over age 25 with one station in particular focusing on the African American population. The format included either 10 or 30-second segments addressing the six main barriers to early detection of breast cancer as noted in our previous research. One station aired the messages during or after "The Gospel Show" and another just prior to the "Delilah" program. The campaign covered a 13-week period and included a total of 404 announcements.

Task 5: Conduct Post-Intervention Survey, Months 37-47

a. Contact individuals in pre-intervention sample

An interviewer training session was conducted on October 12, 2000. Seven of those trained had to resign because of full time job opportunities or family health obligations. Finally, we had 18 active, dependable experienced interviewers, nine in each county, with seven being African American. Using copies of the census forms from the pre-intervention survey, this group attempted to contact as many of the previous sample as possible. As anticipated, we had many addresses that were no longer accurate due to relocation caused by Hurricane Floyd and the subsequent flooding. In addition, other reasons we were unable to conduct the interview included the subject was too sick to participate or had died, the subject had developed breast cancer since our previous interview, the subject declined to be interviewed, or the subject did not keep scheduled appointments. In this latter case, subjects were re-assigned to another interviewer in an attempt to persuade them to complete the interview. (See Appendix B for a copy of the training manual.)

b. Contact individuals identified in the new census process

The interviewers collected data on women in the appropriate age range in both counties in an effort to identify a new sample of women to interview for the post-intervention survey. The total number of interviews successfully completed was 1417 with 742 of these representing women who completed both the pre- and post-intervention interviews. (See Appendix C for the census form and the Time 2 interview. See Appendix D for the Time 1 interview.)

Task 6: Analyze Results and Report Findings, Months 41-60

Before the analysis of the data could be completed, we encountered problems with the system being used to scan the twenty-four pages of each interview. First, the automatic document feeder of the scanner was defective and had to be replaced. This caused a delay of several weeks. Later, a problem developed with the Teleform software program used to interpret the scanned forms causing yet another long delay.

Currently, all the interviews have been successfully scanned and preliminary data analysis is underway. Demographic data for the pre- and post-intervention samples can be found in Table 1 (see Appendix A). This also indicates the ethnicity and age brackets for the matched sample (i.e., those subjects who completed both interviews). The distribution of ethnicity and age are similar in both the intervention and control counties.

One of the first items we will analyze concerns where women obtain information about breast cancer (question 54 from Time 1 interview and question 31 from Time 2). The results from these items are shown in Table 2 (see Appendix A). For the pre-intervention group, the African American women in both Wilson and Pitt Counties obtained more

information from television as did the white women in Wilson County while the white women in Pitt County rated television, magazine article, and pamphlet all very high. Changes were noted in the post-intervention group when both racial groups in both counties indicated pamphlets were a major source of information and white women in each county continued to rely on television.

A preliminary analysis of the changes in women's beliefs about cancer (question 53 from Time 1 interview and question 30 from Time 2) is shown in Table 3 (see Appendix A). For the belief, "air getting to a cancer during surgery will not make it spread," more white women in each county pre- and post-intervention agreed with this, but the percentage of African American women in Pitt County who agreed doubled after the intervention. Another change concerned the belief about "doctors experimenting with people by cutting on their cancers." The percentage of African American women in each county who agreed dropped dramatically from more than 50% to less than 40%. This belief was held by less than a third of the white women. There was a notable change in Pitt County concerning the belief that "nothing works to cure cancer so that it never comes back." In Wilson County this belief decreased somewhat among African Americans, but remained constant among white women. The percentage of women who agreed "if a cancer is cut open in surgery, it will not grow faster" increased more in Pitt County than in Wilson County. In the Time 2 surveys, the number of women of both racial groups in both counties who believed that "a person with high blood is more likely to get cancer than a person with normal blood" dropped to less than 10%. Confidence in "chemotherapy and radiation working better than alternative therapies to treat cancer" decreased especially among African American women in each county. The belief that "if air gets to a cancer during surgery, the cancer will grow faster" dropped precipitously especially among African American women in each county. The percentage of African American women in Pitt County who believed that "cancer is not caused by dirty blood" increased from 28% to 55% while it remained basically unchanged in Wilson County African Americans. White women in Wilson County also indicated more agreement with this belief. A fatalistic attitude still exists in that, with the exception of African American women in Wilson County, at least 50% of each group in both counties maintains the belief that "no matter what I do, if I am going to get cancer, I will get it." There were marked decreases in believing that "if air gets in the place where the doctor cuts, then the cancer will kill you." Agreement with this statement among African American women in Pitt County dropped from 51% to 30%, but more African Americans than whites in each county held this belief.

Table 4 (see Appendix A) indicates responses concerning actions women would take if they detected a lump or knot in their breasts (question 20 on Time 2 interview) comparing women who had attended a breast cancer program in Pitt County with those who had not attended. Ninety five percent of the African American and 81% of the white attendees replied that they "would go to the doctor immediately." Among those who did not attend a program, 79% of the African Americans and 84% of the whites chose this reply. Delay in seeking treatment for a breast problem has been a consistent problem in eastern North Carolina. Further research is indicated to determine if this response shows an actual change in behavior.

Key Research Accomplishments:

- Completed almost 1200 pre-intervention surveys
- Completed almost 1500 post-intervention surveys
- Developed public service announcements
- Developed educational pamphlets and bookmark
- Conducted educational programs in churches, work sites, organizations, schools
- Broadcasted breast cancer messages on local radio stations
- Conducted intervention through OB/GYN offices
- Conducted intervention through emergency department
- Developed questionnaire to ascertain effectiveness of community intervention

Reportable Outcomes:

Presentations and Publications:

Series of three invited lectures:

"Using Ethnographic Methods for Educational Media Development" and "Qualitative Research on Breast Cancer: Linking Theory and Methods," to faculty and Students in the College of Public Health, University of South Florida, June 13, 2001.

"The Influence of Socioeconomic and Cultural Factors on Racial Differences in Late Stage Presentation for Breast Cancer," in the Research Seminar Series of the Moffitt Cancer Center, University of South Florida, Tampa FL, June 14, 2001.

Grants Submitted but not funded:

"Cultural Beliefs and Breast Cancer Behavior in Elderly Women," submitted to the Department of Health and Human Services for the National Institute on Aging Initiative.

"East Carolina and the East Carolina Breast Cancer Awareness Program," submitted to the National Alliance of Breast Cancer Organizations for the "Within Our Reach" program.

Article accepted:

Earp, JAL, Eng, E, O'Malley, MS, Altpeter, M, and Mathews, HF. "Increasing the Use of Mammography among Older, Rural, African American Women: Initial Results From a Controlled Trial," *American Journal of Public Health*.

Articles published:

Mathews, HF. "Negotiating Cultural Consensus in a Breast Cancer Self-Help Group," *Medical Anthropology Quarterly* 14(3): 394-413.

O'Malley, MS, Earp, JAL, Hawley, ST, Schell, MJ, Mathews, HF, Mitchell, J. "The Association of Race/Ethnicity, Socioeconomic Status, and Physician Recommendation for Mammography: Who Get the Message about Breast Cancer Screening?" *American Journal of Public Health* 91(1): 49-54.

Pololi L, Lannin DR, Mathews HF, Mitchell J, Swanson MS, Swanson FH. "The Need For Culturally Based Breast Cancer Education for Women Living in North Carolina." *Medical Encounter: A Publication of the American Academy on Physician and Patient* 15(4): 10-11.

Tafra L, Lannin DR, Swanson MS, Verbanac KM, Chua AN, Ng PC, et al. "Multicenter Trial of Sentinel Node Biopsy for Breast Cancer Using Both Technetium Sulfur Colloid and Isosulfan Blue Dye." *Annals of Surgery* 233(1): 51-59.

Abstracts:

Lannin DR, Mathews HF, Mitchell J, Swanson, MS, Swanson, FH, Pololi L. "The Need for Culturally Based Breast Cancer Education for Rural African American Women," Era of Hope, Department of Defense Breast Cancer Research Program Meeting. Atlanta, June 8-11, 2000.

Lannin DR, Cuenca R, Chadwell T, Iheanacho M, Tafra L. "Comparison of Three Methods for Breast Lymphatic Mapping," Sentinel Node 2000, 2nd International Sentinel Node Congress, Santa Monica, December 2000.

Tafra L, Swanson MS, Verbanac KV, Lannin DR. "Preoperative Chemotherapy and Sentinel Node Biopsy for Breast Cancer," American Society of Breast Surgeons, 2nd Annual Meeting, La Jolla, May 2001.

Conclusions:

During the current one-year extension period to complete our four-year project, we continued our intervention programs in the target county and upon completion of those, began the post-intervention survey phase. There were two sample populations to be included in the post-intervention survey. The first was the original sample surveyed prior to the initiation of the interventions. Of these 1081 women, we were able to recontact and complete a survey with 742 for a 69% resurvey rate after a three-year period. We think this is a very good completion rate given the disruptions to residential areas caused by the flooding from Hurricane Floyd. This return rate should help us assess rates of change in the baseline population because of our intervention. The second population was a random sample of women newly identified for the post-intervention survey. We completed surveys with an additional 650 women in this portion of the study.

The original purpose of the four-year project was to develop methods to encourage the earlier detection of breast cancer in rural African Americans. Our focus was on the cultural and psychosocial beliefs which we demonstrated in a previous study contributed to patient delay in seeking treatment for the symptoms of breast cancer. We are especially gratified to see, in our preliminary analyses of the post-intervention survey, that we appear to have been successful in modifying adherence among African American women to several of the beliefs we specifically targeted in the interventions. These include the belief that air getting to a cancer will cause it to spread, that surgery is not an effective form of treatment for cancer, and that cutting on a cancer will make it grow larger.

Our assumption is that belief is the basis for intention to take action so that women whose beliefs cause them to doubt the efficacy of medical treatments will be more likely to present with late stage disease. It is particularly significant, therefore, that women in the post-intervention survey who had been to one of our educational programs reported a shift in their intention to act, stating that they would see a doctor immediately if they had detected a breast problem. This change was not as significant for those who had not attended a program.

During the final three months of the project, we will more completely analyze the results of the post-intervention survey in order to determine the extent to which our intervention efforts appear to have influenced not only attitudes and beliefs about breast cancer but also the degree to which these attitudes correspond to changes in actual behaviors such as rates of breast cancer screening and measures of intention to take action.

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Appendix A

Table 1. Ethnicity and Age in Pitt and Wilson Counties for Completed Pre-Intervention, Post-Intervention and Matched Interviews

	N = 1081 Pre-Intervention n (%)	N = 1417 Post-Intervention n (%)	N = 742 Matched n (%)
Pitt County	550 (51)	740 (52)	394 (53)
Black	234 (42)	275 (37)	169 (43)
White	316 (58)	465 (63)	225 (57)
Wilson County	531 (49)	677 (48)	348 (47)
Black	245 (46)	383 (57)	166 (48)
White	286 (54)	294 (43)	182 (52)
Pitt County			
19-39	176 (32)	219 (30)	87 (22)
40-64	230 (42)	344 (46)	179 (45)
65+	144 (26)	177 (24)	128 (33)
Wilson County			
19-39	172 (32)	183 (27)	88 (25)
40-64	198 (37)	280 (41)	145 (42)
65+	161 (30)	214 (32)	115 (33)

Table 2. Sources of Information about Breast Cancer Reported by Blacks and Whites at the Pre-Intervention and Post-Intervention Interviews in Pitt and Wilson Counties

Sources of Information	Pre-Intervention % Yes				Post-Intervention % Yes			
	Pitt		Wilson		Pitt		Wilson	
	B	W	B	W	B	W	B	W
Television	75	82	76	85	61	84	58	84
Magazine Article	55	83	44	79	47	75	57	80
Radio	42	40	54	43	56	54	46	47
Newspaper	34	62	43	67	36	68	33	74
Church Program	13	5	9	1	13	3	9	13
Civic Group Program	3	8	5	8	4	8	6	8
Program at Work	9	9	9	9	11	11	10	7
Pamphlet	71	83	68	71	79	86	78	85
Video	18	19	17	11	22	18	12	10
American Cancer Society	6	15	7	16	4	16	6	21
Health Fair	34	22	22	20	20	28	20	24

Table 3. Beliefs About Breast Cancer Reported by Blacks and Whites at the Pre-Intervention and Post-Intervention Interviews in Pitt and Wilson Counties

Sources of Information	Pre-Intervention % Agree				Post-Intervention % Agree			
	Pitt		Wilson		Pitt		Wilson	
	B	W	B	W	B	W	B	W
If a cancer is cut open in surgery, it will not grow faster.	25	50	38	34	42	57	45	39
Negative feelings can cause cancer.	10	23	12	19	13	17	12	17
If a person has cancer, there is no sense trying to do anything about it.	3	2	2	1	1	1	2	1
People who take good care of themselves usually don't get cancer.	22	23	26	14	14	14	14	15
A person with high blood is more likely to get cancer than a person with normal blood.	17	16	20	11	6	10	10	7
Vaccinations weaken the immune system which can lead to cancer.	8	4	16	8	8	3	10	4
Luck plays a big part in determining who gets cancer.	6	20	12	15	7	20	8	13
It is better to die whole than to let a doctor cut on your body.	8	3	17	3	9	3	8	2
Chemotherapy and radiation work better than alternative therapies to treat cancer.	66	71	67	76	49	66	50	73
If air gets to a cancer during surgery, the cancer will grow faster.	64	32	64	41	46	25	49	40
Cancer is not caused by dirty blood.	28	70	37	56	55	74	38	69
Doctors and health professionals are the ones I would trust most to decide how to treat cancer.	91	96	88	94	91	96	92	97

Table 3. Beliefs About Breast Cancer Reported by Blacks and Whites at the Pre-Intervention and Post-Intervention Interviews in Pitt and Wilson Counties

Sources of Information	Pre-Intervention % Agree				Post-Intervention % Agree			
	Pitt		Wilson		Pitt		Wilson	
	B	W	B	W	B	W	B	W
Antibiotics weaken the immune system which can lead to cancer.	12	9	18	11	10	9	13	13
Someone can give you cancer by putting a root on you.	2	0	3	<1	3	<1	2	0
People get cancer when they are tired and their resistance is down.	11	26	14	16	11	17	15	14
Visualizing your body attacking cancer cells will not help to cure the disease.	32	45	44	43	47	48	41	49
Air getting to a cancer during surgery will not make it spread.	18	54	23	43	36	63	37	46
If you keep thinking you have cancer, you will probably get it.	27	16	17	11	32	56	50	34
Herbal remedies are more effective than medicines against cancer.	14	7	21	4	12	6	12	9
Doctors experiment with people by cutting on their cancers.	54	29	52	34	39	28	39	31
People with thin blood are more likely to get cancer.	10	5	17	3	7	3	7	3
Nothing works to cure cancer so that it never comes back.	41	38	37	43	22	28	28	44
Positive feelings can help cure cancer.	52	89	57	77	77	84	67	83

Table 3. Beliefs About Breast Cancer Reported by Blacks and Whites at the Pre-Intervention and Post-Intervention Interviews in Pitt and Wilson Counties

Sources of Information	Pre-Intervention % Agree				Post-Intervention % Agree			
	Pitt		Wilson		Pitt		Wilson	
	B	W	B	W	B	W	B	W
No matter what I do, if I am going to get cancer, I will get it.	58	66	58	56	50	58	42	58
If air gets in the place where the doctor cuts, then the cancer will kill you.	51	11	39	17	30	7	36	10

Table 4. Response to "Finding a Lump or Knot on a Breast" Among Black and White Attendees and Non-Attendees of a Breast Cancer Program in Pitt County

Question 26	Black Attended		White Attended	
	N=59 Yes %	N=216 No %	N=89 Yes %	N=376 No %
If I found a lump or knot in my breast that did not bother me, I would:				
Leave it alone and do nothing:	0	1	2	<1
I might or might not go to the doctor.	0	1	1	2
I would probably go to a doctor.	5	18	16	12
I would go to the doctor immediately.	95	79	81	84

Appendix B

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PROJECT GOAL

The major reason that some women in our region have poor survival from breast cancer is that they present with advanced stage disease. Our previous research has indicated two reasons for late stage breast cancer presentation in this population: (1) lack of breast screening including clinical exam and mammography, and (2) patient delay due to cultural and psychosocial beliefs. The goal of this project is to develop methods to encourage earlier detection of breast cancer in our area. A community-wide intervention began in early 1999 in an attempt to promote breast screening and alter those cultural beliefs and practices that may cause some women to delay getting treatment. The intervention utilized educational messages through television, radio, and newspaper; educational programs conducted through local churches, businesses and schools; and a unique program where older women are reached through their younger relatives who are seeing Ob-Gyn physicians.

PURPOSE OF SURVEYS

The educational intervention was performed in the experimental county, Pitt County, and the effects will be compared to a control county, Wilson County, where no intervention was performed. Community-wide surveys are being done in each county before and after the intervention to determine how well the intervention affected the area. The two counties were chosen because they have similar populations and a similar range of medical facilities. This four year study consisted of data collection and assessment in years one and four and the intervention in years two and three.

ROLES AND RESPONSIBILITIES OF AN INTERVIEWER

Be familiar with the purpose and importance of the project so you can answer questions about the project.

Remember that all of the women you will be interviewing have spoken with an interviewer before. We call the women we speak to, **Respondents**. These respondents want to be heard and are usually happy that they are given an opportunity to talk. They are often willing to share their thoughts if they are convinced that their responses will be of some help to others. If you, as an interviewer, believe that the information obtained from the survey is important, your tone and manner will convey that importance to the respondents.

Know how to confront problems and less-than-ideal circumstances "in the field."

Most problems will be minor and can be handled as they occur. For example, should an unexpected emergency (i.e car problems, etc.) result in the delay or cancellation of a scheduled interview, be responsible enough to call and inform the respondent.

More serious problems (i.e your inability to fulfill your role as an interviewer) should be brought to the attention of the project manager, Frances Swanson. Her phone number is 252 816-5418.

Keep what is learned about respondents confidential.

Everyone working on this project must maintain confidentiality. All information obtained during the interview that concerns respondents or their families is privileged information. You should never talk about a respondent's answers or use her name. Information should not be shared with your family, friends, or other respondents. The information may only be shared with the project personnel listed in this manual. We expect all interviewers to follow this rule.

Be attentive to your appearance.

Your appearance is important to a successful interview. Please dress in an appropriate, professional manner. We want you to be comfortable, but we also want respondents to feel comfortable around you.

Also, certain personal habits such as smoking and chewing gum may turn respondents off. Please do not engage in such activities once you arrive at a respondent's home.

Put the respondent at ease so that she will feel free to answer personal questions.

The best way to do this is to be and feel relaxed. Show a compassionate attitude and an interest in the respondent's answers.

Although it is your responsibility to listen attentively, you should always maintain a certain degree of personal distance. For example, if the respondent shifts the conversation to topics not relevant to the interview, direct her back to the survey.

Personal safety should always be considered.

Some suggestions for maintaining your personal safety include:

-Try to schedule interviews during daylight hours. If you must schedule one at night, ask the respondent to leave a light on for you.

-Do not wear a lot of expensive jewelry and consider locking any valuables in your trunk if you do not want to carry them with you.

-Do not go into any situation where you feel uncomfortable. For example, if a threatening dog is present or if other people in the home seem threatening, leave and telephone the respondent as soon as possible to reschedule.

-Do not hesitate to terminate an interview if you feel threatened. Do not jeopardize your safety under any circumstances.

INTERVIEW PROCEDURES

How were women selected?

The women were identified in a door-to-door census conducted in Pitt and Wilson counties. A random sample of women were selected in each age group from the two county area. Census forms with names, addresses, and telephone numbers of the women selected will be given to each interviewer to contact.

How to contact the women on your census forms?

Once you have received the names of the women you are to interview, you need to contact them to set up appointments for the interviews. If there is no phone number listed on the form, you must reach them by direct contact by visiting the woman's home. This visit can be to set up an appointment or you can try to conduct the interview at that time.

Guidelines:

- 1- Interview only the women whose names are on the forms you are given. Never interview someone whose name is not on the census forms. Maintaining the random selection of the sample is vital to the scientific accuracy of this study.
- 2- Plan your trips so that you can interview more than one person in the area, if at all possible. Schedule plenty of time between appointments.
- 3- Be punctual and avoid changing appointment times. If a woman is not home or breaks an appointment, contact her as soon as possible to reschedule. If **you** have to change an appointment, apologize to the respondent and reschedule the appointment at **her** earliest convenience.
- 4- All interviews must be conducted in person. It is not acceptable to interview someone over the telephone. If a respondent asks you to do the interview over the phone, tell her that you need to do it in person because you must show her certain parts of the interview.

HOW TO RESPOND TO RESONDENTS' REFUSALS

Respondent: "I don't have time to do this."

You: "It should only take about 45 minutes to one hour to complete the interview. I'm very flexible and we can do it any time that is good for you."

Respondent: "I'm really not interested."

You: "It is very important that we interview everyone whose name was picked so we have a good understanding of what women think in your area. If we don't talk to everyone, the results won't be very helpful. So if you would please reconsider, I would greatly appreciate."

Respondent: "I don't have any health problems."

You: "We are interested in interviewing all women even if they don't feel that they have any health problems. Interviewing everyone helps us look at things that may affect good as well as bad health."

Respondent: "I don't like studies like these."

You: "We understand that many people don't like to be asked a lot of personal questions, but this study is very important to help us learn some things that can hopefully improve the health of women in this county."

Respondent: "My health is no one else's business."

You: "I can certainly understand that you feel this way. If you decide to speak to us, you are being generous with your time. All our interviews are confidential, and your name will not be connected with answers you give. Protecting people's privacy is one of our major concerns. You may skip any questions you want."

Respondent: "I don't think I know enough to try to answer these questions."

You: "These questions are not hard and there are no right or wrong answers. The questions ask for your opinions about certain things like your health and what you do to keep healthy. Some of the women interviewed were concerned at first but were at ease after we got started with the questions."

CONDUCTING THE INTERVIEW

1. **Introduce yourself:** My name is _____ and I am from the EC-BCAP. (Show the letter or card with the phone number.)
2. **Remind the respondent that she was contacted before.** (Census, letter explaining her selection as part of the study, phone call setting up the interview.
3. **Thank her for agreeing to participate** in the project and ask her if she has any questions before you start the interview.
4. **Put the respondent at ease.** Show genuine interest and be relaxed and friendly. Your sincerity and interest in the respondent's feelings and family will help establish empathy.
5. **Keep your introductory remarks brief.** Try to avoid excessive conversation and do the interview as soon as possible. Be courteous and let her know you can talk after the interview is over.
6. **Try to interview the respondent alone.** Ask if there is a place the two of you can go so you will not be interrupted. Let her know the interview will go much faster if there are no interruptions.
7. **You must get the respondent's informed consent to participate in the project BEFORE the interview begins.** These forms must be read and signed before you start the interview. Leave one copy of the informed consent with the respondent and turn in the other one.

Stress that there are no right or wrong answers and that her opinions are very valuable to doctors and to other women like herself. Remind her that she was chosen along with the other women to let us know about their health care experiences.

QUESTIONS OFTEN ASKED

Respondent: "What is this study?"

You: "This interview is part of a study on women's health being conducted by East Carolina University and the Leo W. Jenkins Cancer Center in Greenville. We are doing this study to learn more about health care practices for serious illnesses of women in Pitt County." (Do not say that this interview is about breast cancer or getting mammograms; it could bias the questions.)

Respondent: "Is this private?"

You: "We are very concerned about confidentiality and protecting your privacy. Your name will not be mentioned to anyone and all the results are written up in a way that does not identify any individual. Your answers will never be connected with your name."

Respondent: "What kind of questions do I have to answer?"

You: "The questions are mostly about what you think about taking care of your health. I'll be asking you about illnesses you may have had, things you do to stay healthy, and what you do when you get sick. These are really easy questions and there are no right or wrong answers. We are very interested in your opinion."

Repsondent: "Why did you choose me?"

You: "We used a computer to select women (like the flip of a coin) for us to contact. We interview only the women the computer selects so we may or may not interview any of your neighbors. It is very important to us to talk to all the women on our lists so we can get good information."

HOW TO ASK SURVEY QUESTIONS

There are two types of questions that will be used in the questionnaire: **closed-ended** and **open-ended**.

Closed-ended questions are questions that have response categories on the interview you fill in. Closed-ended questions can end with a question mark (?) or a colon (:). Here are examples of each:

Ex. 1 Have you ever had a mammogram?

- ☐ YES ☐ NO ☐ (S.C. NOT SURE)

Ex. 2 Do you attend church:

- ☐ On a regular basis
☐ Occasionally
☐ On special events or holidays
☐ Never

For a close-ended question, always read the question and all of the possible answers. After this, fill in the circle(s) of the answer(s) given by the respondent. **S.C.** means silent code so **do not read** this answer to the respondent.

Open-ended questions, just have a line for you to write in the answers. Some of these questions will have boxes for you to fill in answers.

Ex. Why haven't you ever had a mammogram?

Write down the respondent's exact words. Begin writing as soon as the respondent begins speaking. It may be helpful to repeat what was said to make sure you write every word.

Things to be careful about when asking questions:

- Use a pleasant tone of voice. Show interest in what the respondent is saying, be confident, and have a professional manner.
- Make eye contact to show you're interested. Don't do things that indicate you might be judging the respondent, like raising your eyebrows or frowning.
- Read questions slowly.
- Read each question exactly as it is written. ADD nothing. SKIP nothing.
- Emphasize underlined words with your voice to give them more meaning.
- Don't forget to read transition statements that begin a section. These statements help set the tone for the questions that follow.
- Don't read out loud our instructions to you. These instructions will be labeled {INTER} and are in **boldface print**. Remember, S.C. means Silent Code. Answers with S.C are not intended to be read out loud.
- Read the entire question and all multiple answers to the respondent before accepting the respondent's answer. If the question ends with a question mark (?), you may not have to read the answers. If the question ends with a colon (:), you will need to read all of the answers to the respondent. When a question has a card with it, point to the answers on the card as you say them.
- Don't skip questions unless the questions say to do so. If the respondent has already given you information that answers the question, you can comment:
 "I know we've talked about this..." or "I know you just mentioned this but I need to ask every question as it is written in the questionnaire."

To get accurate information from respondents, it is important that you ask all questions in a uniform manner. That is, ask all respondents the same questions in the same way and in the same order.

If a respondent doesn't understand the question, don't try to explain to her what you think the question means. Instead, use one of the following methods:

- Repeat the entire question. Use this technique if you think the respondent didn't hear the question.
- Repeat part of the question. Use this technique when the respondent is unsure of what you are asking.
- Repeat all possible response categories if the respondent asks you to repeat any of them.
- Use the vocabulary list at the end of the manual to give the definitions of some of the difficult words in the brochure. Take the vocabulary list to each interview to insure consistency.

Giving different explanations, synonyms, or clarifications to different respondents means the questions are not being asked in a uniform or standard manner. This also means the questions won't be the same questions for all respondents. When this happens, we can't be sure the answers are what the women really think or believe.

RECORDING ANSWERS

The interview booklet is printed in *Teleform* format. All of the answers to the questions will be scanned into the computer rather than manually entered. The scanner is very sensitive so it is very important that the answers be recorded correctly.

Guidelines for recording answers:

- Always use the black felt tip pens that were provided. Extra pens will be available through the main office when they are needed.
- When filling in boxes, print neatly IN ALL CAPS so that each letter fits in a square. Skip spaces between letters and numbers that look similar.

Ex. The letter "I" should be printed with the bars so it does not look like the number "1."

- Fill in the circles completely, trying not to stray outside of it. If you mark an incorrect answer, place an "X" on the wrong answer then fill in the circle of the correct answer.
- Try to avoid making stray marks on the interview. Take extra paper in case you need to make personal notes or messages.

FEEDBACK

You can provide feedback to reward the respondents for giving thoughtful answers.

- Give short feedback for short responses like:
“I see...”
“Uh-huh”
“Thank you”
“Thanks”
- Give longer feedback when the respondent gives longer or more complicated answers:

“That’s useful/helpful information”
“It’s useful to get your ideas on this”
“It’s important to get your opinion on this, thank you”
“I see; that’s helpful to know”
“It’s important to find out what women think about this”
- Pause before giving feedback. Your pause signals the respondent that you have considered her answer carefully.
- Don’t give feedback if the respondent goes off track or doesn’t answer the question.

Feedback should not be judgmental or show support for one answer over another. For example, don’t say “I agree with you on that” or “That’s very good.” This could bias the women to give answers she feels will please you.

PROBING

Probes are used when a respondent's answers are unclear. Probing helps to clarify the respondent's answers or to focus the respondent on the specific content of the question and answer.

Ex. You: Different women have told us what they would do. How likely would you be to go to the doctor if you found a lump?
Would you be:
o very likely o likely o not likely

Respondent: I would say likely or very likely.

This response is unclear because the respondent did not choose one of the three options. The respondent must be asked in a neutral way to clarify which option she would like to choose. Do not fill in two responses. Try to get respondent to give you one answer.

Some examples of neutral probes are:

- Pause for a while. A pause gives the respondent time to be more thoughtful when answering.
- Repeat the question or part of the question. This involves simply repeating the response choices. Repetition is used if the respondent does not seem to understand the question or needs more to think.
- Ask clarifying questions.
 - “What do you mean?”
 - “Would you tell me more about your thinking on that?”
 - “What do you think?” or “What do you expect?”
 - “Which would be closer to the way you feel?”

Pauses and repetition of the question are the best neutral probes to use when appropriate.

HELPFUL TIPS ABOUT QUESTIONNAIRE

Consent forms:

Be sure BOTH you and the person being interviewed have signed the consent form. Recheck before you turn in.

Block letters for boxes:

For answers in boxes (as on page 1) be sure to use CAPITAL LETTERS and do not let your letters/numbers touch the sides of the box. This mistake causes an error to appear on each answer and takes time to correct on the computer that could easily be avoided. Question #15 is NOT an example of this so just use your best handwriting so another person could read it easily.

Skip patterns:

Please be careful to read the directions for each question. If the question indicates that a skip should occur if answered a certain way, please make sure to skip to the correct question. See question #11 as an example of a question with a (skip to...) direction.

Omitting parts or entire question:

Please make certain you go slowly and do not miss or accidentally skip any questions. Always re-check each interview before turning in. YOU will need to re-contact the person if you have omitted any questions and will be paid when the interview is completed.

Writing on questionnaire:

Please do not write on the questionnaire. Attach sticky notes that are visible to us (make sure they stick out to alert us). If a sticky note is too small for your message, attach (with a paper clip, NOT a staple) a sheet of paper to the front of the questionnaire. Be sure to mark clearly the ID # and the question # on the paper.

Block answers:

Here are examples for coding when the subjects do not answer certain questions:

Statement	example	fill in block answer box
"don't know"	#41 where lived longest	DK
"don't know"	social security #, phone #	1111111
"refused to answer" for answers requiring numbers	social security #, phone #	9999999
"refused to answer" for answers requiring letters	#28 relationship	ZZZZZZZZ

Educational intervention:

For the time 2 questionnaire (2000) there are ten questions (**#51-60**) to evaluate the effectiveness of our educational intervention. For each of these questions, you will show the respondent a different picture or pamphlet and ask if she has seen it. If she replies, "yes", then you will follow up by asking where she saw it and who showed it to her. There are instructions for the interviewer at the beginning of each question to indicate which picture or pamphlet to show the respondent. Be careful to **use the correct one!**

Ex. 1 Have you seen this breast cancer brochure before?

☐ YES

☐ NO

Where did you see this brochure? _____

Who showed it to you? _____

PLEASE CALL US IF YOU HAVE ANY QUESTIONS!

EDITING

Editing means rechecking the interview questionnaire after the interview, and out of the sight of the respondent, to be sure it is complete. Editing should be done as soon as possible after you have finished the interview.

- Make sure you fill in all the items on the cover page and the back page. Be sure to include your interviewer number, date of the interview, and the respondent's information.
- Review the interview to be sure that every question that should be answered has a response. It is a good idea to check this before leaving the respondent's home or while you are in the car before you leave the area. If anything is missing, it is likely that you will have to contact the respondent again to get the information.
- Make sure the answers to the open-ended questions are written legibly. Fill in any words where you may have used shorthand during the interview.
- Be sure to write your comments in the space provided on the last page.

CONTACTING PREVIOUS RESPONDENTS

In this particular study, we are re-interviewing respondents from our previous interviews which were conducted in 1998. During the interval, we have been conducting an educational intervention in the experimental county (Pitt) which included public service announcements (PSA'S) on television, newspaper advertisements, distribution of pamphlets at health fairs and the malls as well as programs at churches, schools, and civic organizations where we showed our educational video. We now want to interview as many of the same people as possible from the Time 1 interviews.

In anticipation of this, we asked the respondent for the names, addresses, and phone numbers of two contact people in case the respondent re-located before the Time 2 interview. This page of the questionnaire is attached to the census form for each respondent. If you cannot locate the respondent at the previous phone number or address, you will need to call/visit one of the two contact persons.

There will be certain areas in Pitt and Wilson Counties that may have been flooded during Hurricane Floyd causing many people to re-locate. At this point, some people still have not and will not be returning to the 1998 address. Possible strategies to find these respondents include:

- Check local phone book for new listing
- Revisit the house site and ask people in the area
- In a rural area, visit a neighborhood convenience store/gas station to ask if the employees might know how to contact the respondent or others on her contact list.

Please make every effort to interview the previous respondents since their interviews are crucial to the success of our project, but please be sensitive to the difficulties they have endured.

MATERIALS TO BRING TO EACH INTERVIEW:

- Interview booklet (bring more than one).
- Census forms of those women being interviewed that day.
- Notebook with interview materials including cards, consent forms, and pens.
- Name tag to be worn on your clothing.

INTERVIEWER VOCABULARY

Mammogram: A picture of the breast tissue made by compressing the breast while the picture, a type of x-ray, is taken.

Mammography: The use of a mammogram to detect breast cancer.

Biopsy: The surgical removal of part of the lump to be sent to the laboratory to determine if it is cancer.

Cysts: A fluid-filled sac or cavity that often enlarges and becomes tender and painful, but is benign .

Benign: Without cancer.

Malignant: Cancerous.

Lumpectomy: The surgical removal of the cancerous lump and surrounding tissues.

Mastectomy: The surgical removal of the breast where cancer is found.

Hormone Replacement Therapy: Hormone-containing medicines that offset the symptoms of hormone loss during menopause.

Fibrocystic Disease: Breast irregularities or lumpiness that are not cancerous.

Vaccination: An agent given for the purpose of establishing resistance to an infectious disease.

Antibiotics: Medicines, such as penicillin, used to treat infectious diseases.

Appendix C

PRELIMINARY HOUSEHOLD INTERVIEW
CANCER INTERVENTION STUDY: 2000
East Carolina University

**Fill out a different form for each woman
age 18+ in home willing to be interviewed**

Census Worker

--	--

County:

Community

Block Group Number

☐ Pitt

[illegible]

Wilson

--	--	--	--	--

First Name

[illegible]

Last Name

[illegible]

Number & Street Address

[illegible]

City

[illegible]

State

--	--

Zip Code

	-	
--	---	--

Age

--	--

Date of Birth:

		/			/		
--	--	---	--	--	---	--	--

Race

☐ White

☐ Black

☐ Other

Had Breast Cancer?

☐ Yes☐ No

(Area Code)

Telephone Number
$$(\begin{array}{|c|} \hline \\ \hline \end{array} \begin{array}{|c|} \hline \\ \hline \end{array} \begin{array}{|c|} \hline \\ \hline \end{array}) \begin{array}{|c|} \hline \\ \hline \end{array} \begin{array}{|c|} \hline \\ \hline \end{array} \begin{array}{|c|} \hline \\ \hline \end{array} - \begin{array}{|c|} \hline \\ \hline \end{array} \begin{array}{|c|} \hline \\ \hline \end{array} \begin{array}{|c|} \hline \\ \hline \end{array} \begin{array}{|c|} \hline \\ \hline \end{array}$$

Best day of week to be found at home?

☐ Mon ☐ Tue ☐ Wed ☐ Thu ☐ Fri ☐ Sat ☐ Sun

(may check more than one)

Best time of day to be found at home?

☐ morning ☐ afternoon ☐ evening

(may check more than one)

Directions to the Home:

19643

Breast Cancer Project

Time-2 Survey

Leo W. Jenkins Cancer Center

East Carolina University

Subject ID#

--	--	--	--

Interview Date

		/			/		
--	--	---	--	--	---	--	--

Interviewer

--	--

Last Name (same as on census forms)

--	--	--	--	--	--	--	--	--	--	--	--

First Name

--	--	--	--	--	--	--	--	--	--

Mailing Address:

(with town
and zip code)

--

Street Address (if different):

--

Social Security #

			-				
--	--	--	---	--	--	--	--

Phone number

			()				-			
--	--	--	---	--	--	--	---	--	--	--	---	--	--	--

ACCESS TO HEALTH CARE: *Let's begin by talking about some of the health care services that you may use.*

1. Do you have a doctor that you think of as your own doctor? One that you see for most of your health needs?

☐ Yes

☐ No

☐ S.C. (Don't see an MD)

2. What type of doctor is he/she?

{INTER: Hand R. Card #1. Fill in correct circle below.}

☐ a family doctor

☐ a general internist

☐ an OB/GYN

☐ a specialist

☐ or some other type of doctor

☐ S.C. (don't know)

ID# _____

3. Is your doctor a man or a woman? ☐ Man ☐ Woman ☐ S.C. (don't see the same doctor each time)
4. When was the last time that you went to see this doctor? Was it:
☐ Within the past six months ☐ Within the past year ☐ Within the past two years ☐ Within the past five years
5. Has this doctor ever done any of the following things:
- | | |
|--|--|
| a) talk with you about your risk of breast cancer - - - - - | <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> S.C. (not sure) |
| b) examine your breasts for knots or lumps - - - - - | <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> S.C. (not sure) |
| c) ask you whether you examine your own breasts for lumps/knots - - - | <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> S.C. (not sure) |
| d) show you how to examine your own breasts for lumps/knots - - - - . | <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> S.C. (not sure) |
| e) show you a breast model - - - - - | <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> S.C. (not sure) |
| f) talk with you about mammography - - - - - | <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> S.C. (not sure) |
| g) recommend that you get a mammogram - - - - - | <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> S.C. (not sure) |
| h) actually make an appointment or give you a referral for a mammogram | <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> S.C. (not sure) |
| i) ask if your mother or grandmother had breast cancer - - - - - | <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> S.C. (not sure) |
6. If you saw an OB/GYN in the last year, did he/she do either of the following:
- | | |
|---|--|
| -- ask you to share information about breast cancer with your older female relatives | <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> S.C. (not sure) |
| -- give you any written information, like a pamphlet, on breast cancer, breast self-exam or mammography | <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> S.C. (not sure) |
| -- did not see an OB/GYN | <input type="radio"/> Yes |

Screening. Now let's talk about the things that you may have done to protect yourself against breast cancer.

7. Has a doctor or other medical professional ever shown you how to examine your breasts for knots or lumps?

- ☐ Yes ☐ No ☐ (S.C. not sure)

8. Have you ever felt your own breasts in the way a doctor or nurse does to check for knots or lumps?

- ☐ Yes ☐ No ☐ (S.C. not sure)

IF YES, do you check your own breasts:

- ☐ Every day
☐ Several times a week
☐ Several times a month
☐ Once a month
☐ A few times a year
☐ Almost never

9. When did a doctor or nurse last examine your breasts? Was it:

- ☐ More than 3 years ago ☐ Within the past 3 years ☐ Within the past 2 years ☐ Within the past year ☐ Never

10. A mammogram is a picture of the breast tissue made by compressing the breast while the picture, a type of x-ray, is taken. Have you ever heard of a mammogram?

- ☐ Yes ☐ No ☐ (S.C. Not sure)

11. Have you ever had a mammogram?

- ☐ Yes ☐ No **(SKIP to 14)** ☐ (S.C. Not sure)

12. Was your last mammogram:

- ☐ More than 3 years ago ☐ Within the past 3 years ☐ Within the past 2 years ☐ Within the past year

13. What was the main reason you decided to have your last mammogram?

- ☐ Your doctor or nurse recommended it
☐ You thought you might have a breast problem
☐ You were worried about your chances of getting breast cancer
☐ It is recommended for women of your age to have one
☐ Someone other than your doctor or nurse encouraged you to do it
☐ Saw a program on TV
☐ Heard a talk at church or club
☐ Younger relative encouraged me to do it
☐ Because you were interviewed before about breast cancer
☐ Other (write R's exact words) _____

14. Have you ever had breast cancer?

- ☐ Yes ☐ No (**SKIP to 16**) ☐ (S.C. not sure)

15. Thank you for answering my questions up to now. Some of them may have been hard for you. Would you be willing to tell me more about how your breast cancer was first found and about doctor or hospital visits you had afterwards?

Perceived Risk. *Now let's talk about how worried you are about your risk for developing breast cancer.*

16. How likely do you think it is that you will get breast cancer in your lifetime? Do you think it is:

- ☐ Very unlikely ☐ Somewhat unlikely ☐ Somewhat likely ☐ Very likely

17. Compared to most women your age, what do you think the chances are that you will get breast cancer someday? Do you think your chances are:

- ☐ Much lower ☐ Somewhat lower ☐ Somewhat higher ☐ Much higher

18. Overall, how worried are you that you might get breast cancer someday? Would you say that you are:

- ☐ Not worried at all ☐ Somewhat worried ☐ Very worried

BREAST CANCER OPINIONS.

19. *Next I would like to ask you some questions about what you know or have heard about breast cancer. I am interested in what your opinion is about whether these statements are true or false.*

	<u>True</u>	<u>False</u>	<u>(S.C. don't know)</u>
a) Breast cancer is <u>not</u> the most common type of cancer in women. - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b) Mastectomy is removing the breast where cancer is found. - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c) If a woman finds a knot or lump, it is better to do nothing because by then it will be too late.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d) About 1 out of every 8 women in the U.S. will develop breast cancer at some point in her lifetime.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

- | | <u>True</u> | <u>False</u> | <u>(S.C. don't know)</u> |
|--|-----------------------|-----------------------|--------------------------|
| e) You can catch cancer from other people.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| f) The rate at which breast cancers grow is pretty much the same for everyone who gets breast cancer. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| g) A cancer in the breast that is not treated can lead to death.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| h) Lumpectomy is a type of surgery for breast cancer in which the cancer itself but not the whole breast is removed. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| i) As long as a knot or lump doesn't hurt, then it is not cancer.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| j) Chemotherapy is the use of drugs to kill cancerous cells.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| k) Breast cancer <u>does not</u> run in families.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| l) A breast cancer can be cured if it is found early.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| m) African-Americans with breast cancer are more than twice as likely to die from the disease than are white Americans with breast cancer. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| n) If a breast cancer is operated on, it can be stopped from getting any bigger. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| o) More than half of the patients treated by radiation or chemotherapy <u>never</u> experience nausea or vomiting. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| p) Women ages 50 and over should have a mammogram every year.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| q) If a woman finds a knot or lump, the worst that can happen is surgery.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| r) Finding a mass in the breast is not as serious as finding a knot or lump.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| s) Women who get breast cancer lose their breasts.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| t) If untreated, breast cancer will spread to other parts of the body.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

BREAST LUMP ACTIONS. *We are also trying to find out what women would do if they found a lump or knot in their breasts. How likely would you be to do these things?* {INTER: Hand R. Card #2.}

20. If you found a lump or knot in your breast would you:

	<u>Very likely</u>	<u>Somewhat Likely</u>	<u>(S.C. Don't know)</u>	<u>Not likely</u>
a. Wait to see if it becomes painful - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Get a mammogram - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. See a doctor for a breast exam - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Wait to see if the lump or knot gets bigger - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Ask a close friend or relative for advice - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Pray to God about it - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Watch it every day for a while to see if it changes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Leave it alone - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Allow a doctor to do a biopsy (remove a piece of tissue to see if it is a cancer)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

21. Now I'd like to know which of the actions above you think are most important. Which of these would you do first, second, and third? {INTER: Refer R. to Card #2 and enter letter of choice.}

<u>1st action</u>	<u>2nd action</u>	<u>3rd action</u>
A <input type="radio"/>	A <input type="radio"/>	A <input type="radio"/>
B <input type="radio"/>	B <input type="radio"/>	B <input type="radio"/>
C <input type="radio"/>	C <input type="radio"/>	C <input type="radio"/>
D <input type="radio"/>	D <input type="radio"/>	D <input type="radio"/>
E <input type="radio"/>	E <input type="radio"/>	E <input type="radio"/>
F <input type="radio"/>	F <input type="radio"/>	F <input type="radio"/>
G <input type="radio"/>	G <input type="radio"/>	G <input type="radio"/>
H <input type="radio"/>	H <input type="radio"/>	H <input type="radio"/>
I <input type="radio"/>	I <input type="radio"/>	I <input type="radio"/>

22. Assume you had a lump that turned out to be a cancer. If your doctor recommended it, would you have:

{INTER: Fill in all responses given.}

☐ surgery ☐ chemotherapy ☐ radiation ☐ choose no treatment at all

Stages of Change. *These may seem similar to other questions that you have already answered, but they are a little different. I want you to think about what you yourself think or would be likely to do as I ask you these questions.*

{INTER: Read all answers in the set and fill in the circle of the one answer that R. thinks comes closest to what she believes or would be likely to do.}

{INTER: Show R. card #3.}

23. If I get breast cancer:

- ☐ God alone would cure it without help from doctors.
- ☐ God might work through doctors to cure it.
- ☐ God would work through doctors to cure it.
- ☐ Doctors would cure it with help from God.
- ☐ Doctors alone would cure it.

24. If I had surgery for breast cancer:

- ☐ Air getting to the cancer would make it spread faster.
- ☐ Air getting to the cancer might make it spread faster.
- ☐ Air getting to the cancer would probably not make it spread faster.
- ☐ Air getting to the cancer would not cause it to spread faster.

25. If I get breast cancer:

- ☐ I would not tell the man in my life about it.
- ☐ I am not sure if I would tell the man in my life about it.
- ☐ I would most likely tell the man in my life about it.
- ☐ I would definitely tell the man in my life about it.

26. If I found a lump or knot in my breast that did not bother me, I would:

- ☐ Leave it alone and do nothing.
- ☐ I might or might not go to a doctor.
- ☐ I would probably go to a doctor.
- ☐ I would go to the doctor immediately.

27. If I had surgery for breast cancer:

- ☐ Cutting on the cancer would make it spread faster.
- ☐ Cutting on the cancer might make it spread faster.
- ☐ Cutting on the cancer would probably not make it spread faster.
- ☐ Cutting on the cancer would not cause it to spread faster.

Subject ID#

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ID# _____



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- e) A woman is more likely to get support from her female friends or relatives when she is seriously ill than from the man in her life. ☐ ☐ ☐
- f) If a woman has breast cancer, she should tell the man in her life. ☐ ☐ ☐
- g) Women who have surgery for breast cancer are no longer attractive to men. ☐ ☐ ☐
- h) A man should help the woman in his life with her health problems. ☐ ☐ ☐
- i) A man would probably not stay with a woman if he knew that she had breast cancer. ☐ ☐ ☐

BELIEFS ABOUT CANCER.

30. These next items are some of the things different women have told us they believe about cancer. We are interested in your opinions. Please tell us if you strongly agree, agree somewhat, disagree somewhat or strongly disagree with the following statements. Remember, there are no right or wrong answers- we just want your opinion. {INTER: hand R. Card #4.}

- | | <u>SA</u> | <u>AS</u> | <u>(S.C.)
(Not Sure)</u> | <u>DS</u> | <u>SD</u> |
|---|-----------------------|-----------------------|------------------------------|-----------------------|-----------------------|
| a) If a cancer is cut open in surgery, it will not grow faster.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b) Negative feelings can cause cancer.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| c) If a person has cancer, there is no sense trying to do anything about it.- - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| d) People who take good care of themselves usually don't get cancer.- - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| e) A person with high blood is more likely to get cancer than a person with normal blood. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| f) Vaccinations weaken the immune system which can lead to cancer.- - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| g) Luck plays a big part in determining who gets cancer.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

(QUESTION 30 CONTINUED)

	<u>SA</u>	<u>AS</u>	<u>(S.C.)</u> <u>(Not Sure)</u>	<u>DS</u>	<u>SD</u>
h) It is better to die whole than to let a doctor cut on your body.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i) Chemotherapy and radiation work better than alternative therapies to treat cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j) If air gets to a cancer during surgery, the cancer will grow faster.- - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k) Cancer is <u>not</u> caused by dirty blood.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
l) Doctors and health professionals are the ones I would trust most to decide how to treat cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
m) Antibiotics weaken the immune system which can lead to cancer.- - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
n) Someone can give you cancer by putting a root on you.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
o) People get cancer when they are tired and their resistance is down.- - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
p) Visualizing your body attacking cancer cells will <u>not</u> help to cure the disease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
q) Air getting to a cancer during surgery will <u>not</u> make it spread.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
r) If you keep thinking you have cancer, you will probably get it.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
s) Herbal remedies are more effective than medicines against cancer.- - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
t) Doctors experiment with people by cutting on their cancers.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
u) People with thin blood are more likely to get cancer.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
v) Nothing works to cure cancer so that it never comes back.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
w) Positive feelings can help cure cancer.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
x) No matter what I do, if I am going to get cancer, I will get it.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
y) If air gets in the place where the doctor cuts, then the cancer will kill you.-	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

INFORMATION ABOUT BREAST CANCER.

I want to ask you a few questions about any information you may have heard or seen about breast cancer within the past year. Please tell me yes or no for each of the following:

31. Within the past year, have you:

	<u>Yes</u>	<u>No</u>	<u>(S.C.) (Not Sure)</u>
a) Seen a television program or commercial about breast cancer?- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b) Read about breast cancer in a magazine?- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c) Heard a radio program or commercial about breast cancer?- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d) Read about breast cancer in the newspaper?- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e) Been to a <u>church</u> program on breast cancer or mammography?- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f) Been to a program at a <u>club or civic group</u> on breast cancer or mammography?- -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g) Been to a program on breast cancer or mammography <u>at work</u> ?- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h) Seen a pamphlet about breast cancer or mammography?- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i) Seen a video about breast cancer or mammography?- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j) Participated in any local American Cancer Society activities like Relay for Life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k) Picked up information about breast cancer at a health fair?- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

RELIGIOSITY. Many people rely on religion when they are ill. I would like to ask you a few questions about your religious beliefs. Again, there are no right or wrong answers - we are interested in what you think about religion and health.

32. *For the next question, please tell me if you agree or disagree with each statement.*

If you were told that you had breast cancer, would you believe that:

	<u>Agree</u>	<u>(S.C. undecided)</u>	<u>Disagree</u>
a) God would work through the doctors and nurses to cure your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b) You would trust more in God to cure your cancer than medical treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c) You would refuse medical treatment and trust only in God to cure your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d) Only a religious miracle could cure your cancer, not medical treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e) Your cancer would be because you had sinned against God.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f) It would be your responsibility to pray every day that God would cure your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g) The strength of your own faith in God would determine if your cancer was cured.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h) Your prayer alone would do nothing to cure your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i) You would want your church members to come to the hospital to pray with you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j) Your church members praying in church would help to cure your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k) There would be a special ceremony for you in your church to cure your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
l) You would not tell anyone in your church about your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
m) You would not ask people in church to pray for you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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DEMOGRAPHICS: *I just have a few final questions to ask you about your background.*

33. What is your ethnic group or race? Would you say it is:

☐ African-American ☐ Asian ☐ Hispanic ☐ Native American (American Indian) ☐ White ☐ Mixed ☐ Other

34. What was your age on your last birthday and what is your date of birth?

Age		DOB							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>

35. How much schooling have you completed?

- | | |
|--|--|
| <input type="radio"/> Did not go to school | <input type="radio"/> High school degree/GED |
| <input type="radio"/> Less than 4th grade | <input type="radio"/> Some education after high school |
| <input type="radio"/> 4th-8th grade | <input type="radio"/> College degree |
| <input type="radio"/> Some high school | <input type="radio"/> Graduate degree |

36. Are you presently enrolled in school?

☐ Yes ☐ No, out temporarily ☐ No

37. Are you: ☐ Single, never married ☐ Married? ☐ Separated? ☐ Divorced? ☐ Widowed?

If currently married, for how many years?

<input type="text"/>	<input type="text"/>
----------------------	----------------------

ID# _____



38. Who lives with you now?

- 39. Including yourself, how many people live in your household?**

40. How many years have you lived in this community?

41. Have you ever lived anywhere other than eastern NC?

- If Yes, where did you live the longest?**

(City, Town)

For how many years?

42. Do you have a telephone?

- If Yes, what is the number?**

If No, is there a number where you can be reached?

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DEMOGRAPHICS--EMPLOYMENT/INSURANCE STATUS: *These questions are about your employment status and the resources you have available to pay for medical treatments. This information will help us know whether some people have trouble getting the health care they need.*

43. At this time are you:
- ☐ working for pay full time [SKIP to 45]
 - ☐ working for pay part-time [SKIP to 45]
 - ☐ self-employed [SKIP to 45]
 - ☐ not working for pay

44. Are you:
- ☐ retired from paid employment
 - ☐ laid off from a job temporarily
 - ☐ unemployed with disability
 - ☐ unemployed but don't have disability
 - ☐ a student
 - ☐ or have you ALWAYS been a homemaker and not worked for pay [SKIP to 46]

45. What is/was your job called?

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

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HEALTH INSURANCE, OTHER BENEFITS

46. What kind of health insurance do you have? Is it:

[INTER: Hand R. card #5. If two types of insurance are mentioned, fill in both. Fill in all that apply.]

- ☐ Insurance through a private company like Blue Cross
- ☐ Medicare
- ☐ The VA or CHAMPUS
- ☐ Medicaid
- ☐ An HMO or managed care plan
- ☐ Don't know **[SKIP to 48]**
- ☐ Don't have any type of health insurance **[SKIP to 48]**

47. Did you have health insurance last year for:

- ☐ the whole year ☐ or part of the year ☐ (S.C. not sure)

48. At any time in the last year did you not go to the doctor or get medical care because you could not afford it?

- ☐ Yes ☐ No

ID# _____

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FAMILY INCOME

49. Now I would like to ask you about your total family income. Please look at this card. **{INTER: Hand R. Card #6.}** In which of the groups below would you place your total family income? Let me remind you that this information, like all your answers, will be kept completely confidential.

- ☐ 1-under \$5,000
- ☐ 2-between \$5,000 and 7,999
- ☐ 3-between \$8,000 and 11,999
- ☐ 4-between \$12,000 and 15,999
- ☐ 5-between \$16,000 and 24,999
- ☐ 6-between \$25,000 and 49,999
- ☐ 7-over \$50,000
- ☐ 8-(S.C. don't know)
- ☐ 9-(S.C. refused to answer)

50. How many people did this income support last year?

of people supported

--	--

INTERVENTION: *I only have a few more questions to ask you. These questions are about brochures, or other things you may have seen in the past year or two. Please look at each picture or pamphlet I show you and tell me if you have seen it before.*

[INTER: Hand R. "Have You Heard About Breast Cancer" brochure.]

51. Have you seen this breast cancer brochure before?

☐ Yes

☐ No

IF YES:

Where did you see this brochure? _____

Who showed it to you? _____

ID# _____

[INTER: Hand R. "EC-BCAP" bookmark.]

52. Have you seen this breast cancer bookmark before? ☐ Yes ☐ No

IF YES:

Where did you see this brochure? _____

Who showed it to you? _____

[INTER: Hand R. "EC-BCAP" brochure.]

53. Have you seen this breast cancer brochure before? ☐ Yes ☐ No

IF YES:

Where did you see this brochure? _____

Who showed it to you? _____

[INTER: Hand R. "Cathy Hainer" brochure.]

54. Have you seen this breast cancer brochure before? ☐ Yes ☐ No

IF YES:

Where did you see this brochure? _____

Who showed it to you? _____

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[INTER: Hand R. Hallmark Breast Cancer card]

55. Have you seen this breast cancer card before? ☐ Yes ☐ No

IF YES:

Where did you see this card? _____

Who showed it to you? _____

[INTER: Hand R. STEP logo]

56. Have you seen this STEP logo before? ☐ Yes ☐ No

IF YES:

Where did you see this logo? _____

Who showed it to you? _____

[INTER: Hand R. Generation to Generation quiz]

57. Have you seen this breast cancer quiz before? ☐ Yes ☐ No

IF YES:

Where did you see this quiz? _____

Who showed it to you? _____

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[INTER: Hand R. picture of beaded necklace]

58. Have you seen this beaded necklace before?

☐ Yes

☐ No

IF YES:

Where did you see this necklace? _____

Who showed it to you? _____

[INTER: Hand R. EC-BCAP newspaper advertisement.]

59. Have you seen this EC-BCAP advertisement in the newspaper before?

☐ Yes

☐ No

[INTER: Hand R. picture of women in, "To Live On" video.]

60. Have you watched a video called, "To Live On," about six women with breast cancer in Eastern NC? This is a picture of two of the women in the video.

☐ Yes

☐ No

IF YES:

Where did you watch this video? _____

ID# _____

61. We may want to reach you again in the future. In case you move before then, would you please give us the names, addresses, and phone numbers of two people who would know how to reach you.

1.

last name

first name

contact address

contact city

contact state

contact zip-code

()

contact telephone number

2.

last name

first name

contact address

contact city

contact state

contact zip-code

()

contact telephone number



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CONCLUSION

Thank you so much for taking time to talk with me today. Those are all the questions I have for you. Is there anything you would like to ask me about this project?

Are there any comments you would like to add?

TO THE INTERVIEWER:

Please be sure to check over the entire interview to make sure that all questions are answered and that the answers are clearly marked. Also be sure that there are no stray marks on the interview anywhere and that you have filled in the ID# at the bottom of each page. Also, be certain the subject ID boxes on pages 1, 9, and 24 are filled in.

Subject ID#

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ID# _____

Appendix D

Breast Cancer Project
Time-1 Survey
Leo W. Jenkins Cancer Center
East Carolina University

Subject ID# Interview Date / / Interviewer

Last Name (same as on census forms)

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

First Name

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Mailing Address: _____
(with town _____
and zip code) _____

Street Address (if different): _____

Social Security # - -

ACCESS TO HEALTH CARE: *Let's begin by talking about some of the health care services that you may use.*

1. Is there a particular place that you usually go to if you want to see someone about your health?

☐ Yes ☐ No (SKIP to #3) ☐ S.C. (don't know)

2. What kind of place do you usually go to? Is it a doctor's office, a hospital, a clinic, or some other place?

{INTER: Don't read choices. Probe for the one place they go most often, the usual place.}

☐ Doctor's office (either one-person practice or group)

☐ Hospital emergency room

☐ Hospital walk-in or outpatient clinic

☐ Private clinic, not part of medical school

☐ Medical school clinic

☐ Public health department clinic

☐ Community (rural, neighborhood) health center

☐ Military facility

☐ Other (write R's exact words) _____

☐ Don't go to only one place

ID# _____



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3. Do you have a doctor that you think of as your own doctor? One that you see for most of your health needs?
- ☐ Yes ☐ No (SKIP to 9) ☐ S.C. (don't see an MD) (SKIP to 9)

4. What type of doctor is he/she? **{INTER: Hand R. Card #1. Fill in correct circle below.}**

- ☐ a family doctor
- ☐ a general internist
- ☐ an OB/GYN (**SKIP to #10**)
- ☐ a specialist
- ☐ or some other type of doctor
- ☐ S.C. (don't know) (**SKIP to #9**)

5. Is your doctor a man or a woman? ☐ Man ☐ Woman ☐ S.C. (don't see the same doctor each time)

6. Would you please tell me his/her name (or the name of the practice)?

[illegible]

7. When was the last time that you went to see this doctor? Was it:

- ☐ Within the past six months ☐ Within the past year ☐ Within the past two years ☐ Within the past five years

ID# _____



8. Has this doctor ever done any of the following things:

- | | | | |
|---|---------------------------|--------------------------|---------------------------------------|
| -- talk with you about your risk of breast cancer - - - - - | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> S.C. (not sure) |
| -- examine your breasts for knots or lumps - - - - - | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> S.C. (not sure) |
| -- ask you whether you examine your own breasts for lumps/knots - - - | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> S.C. (not sure) |
| -- show you how to examine your own breasts for lumps/knots - - - - | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> S.C. (not sure) |
| -- show you a breast model - - - - - | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> S.C. (not sure) |
| -- talk with you about mammography - - - - - | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> S.C. (not sure) |
| -- recommend that you get a mammogram - - - - - | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> S.C. (not sure) |
| -- actually make an appointment or give you a referral for a mammogram | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> S.C. (not sure) |
| -- ask if your mother or grandmother had breast cancer - - - - - | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> S.C. (not sure) |
| -- give you any written information, like a pamphlet, on breast cancer, breast self-exam or mammography | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> S.C. (not sure) |
| -- ask you to share information about breast cancer with your older female relatives | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> S.C. (not sure) |

9. Do you see an obstetrician/gynecologist (ob/gyn)?

- ☐ Yes, regularly
☐ Yes, sometimes
☐ No, I did in the past, but not now **(SKIP to 14)**
☐ No, never **(SKIP to 14)**

10. Is your gynecologist a man or a woman?

- ☐ Woman ☐ Man ☐ (S.C. don't see the same doctor each time)

11. Would you please tell me his/her name? (Or the name of the practice)

[illegible]

12. When was the last time that you went to see this doctor? Was it:

- ☐ Within the past six months ☐ Within the past year ☐ Within the past two years ☐ Within the past five years

ID#

13. Has this doctor ever done any of the following things:

- talk with you about your risk of breast cancer - - - - - ☐ Yes ☐ No ☐ S.C. (not sure)
- examine your breasts for knots or lumps - - - - - ☐ Yes ☐ No ☐ S.C. (not sure)
- ask you whether you examine your own breasts for lumps/knots - - - ☐ Yes ☐ No ☐ S.C. (not sure)
- show you how to examine your own breasts for lumps/knots - - - - ☐ Yes ☐ No ☐ S.C. (not sure)
- show you a breast model - - - - - ☐ Yes ☐ No ☐ S.C. (not sure)
- talk with you about mammography - - - - - ☐ Yes ☐ No ☐ S.C. (not sure)
- recommend that you get a mammogram - - - - - ☐ Yes ☐ No ☐ S.C. (not sure)
- actually make an appointment or give you a referral for a mammogram ☐ Yes ☐ No ☐ S.C. (not sure)
- ask if your mother or grandmother had breast cancer - - - - - ☐ Yes ☐ No ☐ S.C. (not sure)
- give you any written information, like a pamphlet, on breast cancer, breast self-exam or mammography ☐ Yes ☐ No ☐ S.C. (not sure)
- ask you to share information about breast cancer with your older female relatives ☐ Yes ☐ No ☐ S.C. (not sure)

14. In the past few years have you been to any of the following health care providers or centers:

{INTER: Read each type of provider and fill in the circle each time the R. says YES.}

- | | | |
|---|---|--|
| <input type="radio"/> Chiropractor | <input type="radio"/> Root doctor | <input type="radio"/> Massage therapist |
| <input type="radio"/> Acupuncturist | <input type="radio"/> Biofeedback center | <input type="radio"/> Commercial weight loss program |
| <input type="radio"/> Herbalist | <input type="radio"/> Fortune teller or psychic | <input type="radio"/> Homeopath |
| <input type="radio"/> Health food store | <input type="radio"/> Self-help group | <input type="radio"/> Other (write R's exact words) |
| <input type="radio"/> Religious healer | <input type="radio"/> Hypnotist | _____ |
| | | _____ |

Now, let's talk about your own health.

15. Some people go to the doctor right away, whenever they're worried about their health. Others put off going even when they have a serious problem. Do you usually:

- ☐ go to the doctor as soon as you think something is wrong
- ☐ wait a while and try taking care of the problem yourself
- ☐ wait a while and do nothing to see if it will go away
- ☐ or do you usually not go to the doctor at all
- ☐ (S.C. depends on the type of problem)

ID# _____

Screening. Now let's talk about the things that you may have done to protect yourself against breast cancer.

16. Has a doctor or other medical professional ever shown you how to examine your breasts for knots or lumps?

- ☐ Yes ☐ No ☐ (S.C. not sure)

17. Have you ever felt your own breasts in the way a doctor or nurse does to check for knots or lumps?

- ☐ Yes ☐ No (**SKIP to 18**) ☐ (S.C. not sure)

IF YES, do you check your own breasts:

- ☐ Every day
☐ Several times a week
☐ Several times a month
☐ Once a month
☐ A few times a year
☐ Almost never

{INTER: SKIP to #19 if R. answered YES to #17 and indicated a time interval above.}

18. Why don't you check your own breasts?

{INTER: Fill in all that apply.}

- ☐ You don't know how
☐ You are embarrassed to do it
☐ You're not really worried about knots or lumps
☐ You don't think you would be able to feel a lump if there were one
☐ You would rather not know if there is a problem
☐ You lack privacy to do it regularly
☐ You are too young to start doing it now
☐ You are too old to have to worry about that now
☐ You forget
☐ Other (write R's exact words) _____

ID# _____

19. When did a doctor or nurse last examine your breast? Was it:

☐ More than 3 years ago ☐ Within the past 3 years ☐ Within the past 2 years ☐ Within the past year ☐ Never

20. A mammogram is a picture of the breast tissue made by compressing the breast while the picture, a type of x-ray, is taken. Have you ever heard of a mammogram?

☐ Yes ☐ No ☐ (S.C. Not sure)

21. Have you ever had a mammogram?

☐ Yes (SKIP to 23) ☐ No ☐ (S.C. Not sure)

22. Why do you think that you haven't had one?

(Write R's exact words--then skip to 27)

23. Was your last mammogram:

☐ More than 3 years ago ☐ Within the past 3 years ☐ Within the past 2 years ☐ Within the past year

24. What was the main reason you decided to have your last mammogram?

- ☐ Your doctor or nurse recommended it
- ☐ You thought you might have a breast problem
- ☐ You were worried about your chances of getting breast cancer
- ☐ It is recommended for women of your age to have one
- ☐ Someone other than your doctor or nurse encouraged you to do it
- ☐ Saw a program on TV
- ☐ Heard a talk at church or club
- ☐ Younger relative encouraged me to do it
- ☐ Other (write R's exact words) _____

25. Have you ever had a mammogram that showed that something was wrong with your breasts?

☐ Yes ☐ No (**SKIP to 27**) ☐ (S.C. not sure)

26. Did you have a biopsy of your breast to find out what was wrong on the mammogram?

☐ Yes (**SKIP to 29**) ☐ No ☐ (S.C. not sure)

27. Has any doctor ever told you that you had a lump or tumor in your breast?

{INTER: If R. says that she thinks she has one now, be sure at the end of the interview to recommend that she sees a doctor/nurse.}

☐ Yes ☐ No ☐ (S.C. not sure)

28. Have you ever had a breast biopsy?

☐ Yes ☐ No (**SKIP to 32**) ☐ (S.C. not sure)

29. How many breast biopsies have you had?

--	--

30. Did any of them turn out to be cancer?

☐ Yes ☐ No (**SKIP to 32**) ☐ (S.C. not sure)

31. Thank you for answering my questions up to now. Some of them may have been hard for you. Would you be willing to tell me more about how your breast cancer was first found and about any doctor or hospital visit you had afterwards? **{INTER: If R. has had breast cancer (answered YES to #30), interview ends after answering #31. SKIP to CONCLUSION, p.28}**

ID# _____

32. Have you ever had any problem with your breasts that you decided to wait to see a doctor or nurse about?

☐ Yes

☐ No

IF YES, can you tell me more about the problem and what you did?

(Write R's exact words.)

Perceived Risk. *Now let's talk about how worried you are about your risk for developing breast cancer.*

33. How likely do you think it is that you will get breast cancer in your lifetime? Do you think it is:

☐ Very unlikely

☐ Somewhat unlikely

☐ Somewhat likely

☐ Very likely

34. Compared to most women your age, what do you think the chances are that you will get breast cancer someday? Do you think your chances are:

☐ Much lower

☐ Somewhat lower

☐ Somewhat higher

☐ Much higher

35. Overall, how worried are you that you might get breast cancer someday? Would you say that you are:

☐ Not worried at all

☐ Somewhat worried

☐ Very worried

36. How old were you when you had your first menstrual period? Were you:

☐ younger than 12

☐ age 12-13

☐ age 14 or older

37. Have you given birth to any children (count only children born alive):

☐ Yes

☐ No (SKIP to 39)

38. How old were you when you had your first live birth (count only your first child born alive):

☐ Younger than 20

☐ Between 20-24 years old

☐ Between 25-29 years old

☐ 30 years or older

ID# _____

Family History. Now I would like to ask you a few questions about any of your blood relatives who have had an actual diagnosis of breast cancer. Remember, we are talking about your blood relatives only and not people who are adoptive relatives or who are related to you only by marriage.

39. How many of your blood relatives have had breast cancer? How about your:

- | | | | | | | |
|-------------------|---------------------------|--------------------------|----------------------------------|----------------------|----------------------|------------|
| a. Mother | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Don't know | | | |
| b. Sister(s) | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Don't know | <input type="text"/> | <input type="text"/> | # positive |
| c. Daughter(s) | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Don't know | <input type="text"/> | <input type="text"/> | # positive |
| d. Grandmother(s) | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Don't know | <input type="text"/> | <input type="text"/> | # positive |
| e. Aunt(s) | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Don't know | <input type="text"/> | <input type="text"/> | # positive |
| f. Cousin(s) | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Don't know | <input type="text"/> | <input type="text"/> | # positive |

BREAST CANCER OPINIONS.

40. Next I would like to ask you some questions about what you know or have heard about breast cancer. I am interested in what your opinion is about whether these statements are true or false.

- | | <u>True</u> | <u>False</u> | <u>(S.C. don't know)</u> |
|---|-----------------------|-----------------------|--------------------------|
| 1. Breast cancer is <u>not</u> the most common type of cancer in women. - - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 2. Mastectomy is removing the breast where cancer is found. - - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 3. If a woman finds a knot or lump, it is better to do nothing because by then it will be too late. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 4. About 1 out of every 8 women in the U.S. will develop breast cancer at some point in her lifetime. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |



- | | <u>True</u> | <u>False</u> | <u>(S.C. don't know)</u> |
|---|-----------------------|-----------------------|--------------------------|
| 5. You can catch cancer from other people.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6. The rate at which breast cancers grow is pretty much the same for everyone who gets breast cancer. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 7. A cancer in the breast that is not treated can lead to death.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 8. Lumpectomy is a type of surgery for breast cancer in which the cancer itself but not the whole breast is removed. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 9. As long as a knot or lump doesn't hurt, then it is not cancer.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 10. Chemotherapy is the use of drugs to kill cancerous cells.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 11. Breast cancer <u>does not</u> run in families.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 12. A breast cancer can be cured if it is found early.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 13. African-Americans with breast cancer are more than twice as likely to die from the disease than are white Americans with breast cancer. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 14. If a breast cancer is operated on, it can be stopped from getting any bigger. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 15. More than half of the patients treated by radiation or chemotherapy <u>never</u> experience nausea or vomiting. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 16. Women ages 50 and over should have a mammogram every year.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 17. If a woman finds a knot or lump, the worst that can happen is surgery.- - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 18. Finding a mass in the breast is not as serious as finding a knot or lump.- - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 19. Women who get breast cancer lose their breasts.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 20. If untreated, breast cancer will spread to other parts of the body.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |



BREAST LUMP ACTIONS. *We are also trying to find out what women would do if they found a lump or knot in their breasts. How likely would you be to do these things?* {INTER: Hand R. Card #2.}

41. If you found a lump or knot in your breast would you:

- | | <u>Very likely</u> | <u>Somewhat
Likely</u> | <u>(S.C. Don't know)</u> | <u>Not likely</u> |
|--|-----------------------|----------------------------|--------------------------|-----------------------|
| a. Wait to see if it becomes painful - - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Get a mammogram - - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| c. See a doctor for a breast exam - - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| d. Wait to see if the lump or knot gets bigger - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| e. Ask a close friend or relative for advice - - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| f. Pray to God about it - - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| g. Watch it every day for a while to see if it changes | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| h. Leave it alone - - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

42. Now I'd like to know which of the actions above you think are most important. Which of these would you do first, second, and third? {INTER: Refer R. to Card #2 and enter letter of choice.}

1st action

2nd action

3rd action

- A ☐
B ☐
C ☐
D ☐
E ☐
F ☐
G ☐
H ☐

- A ☐
B ☐
C ☐
D ☐
E ☐
F ☐
G ☐
H ☐

- A ☐
B ☐
C ☐
D ☐
E ☐
F ☐
G ☐
H ☐

Subject ID#

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43. Risk Factors. *Women believe that different things increase their risk of getting breast cancer. Please tell me whether you think these things increase your risk for developing breast cancer. Answer each with yes or no.*

{INTER: read each item as follows:

How about * _____; Would you say it increases your risk for developing breast cancer or not?}

<u>ITEM:</u>	<u>Yes</u>	<u>No</u>	<u>(S.C.) (Uncertain)</u>
*Getting your period early, say before age 12? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
*Eating a high fat diet? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
*Drinking more than 2 alcoholic drinks a day? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
*Having breast implants? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
*Having a family history of breast cancer? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
*Taking birth control pills? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
*Having fibrocystic disease? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
*Heavy smoking? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
*Getting a bump or a bruise to the breast? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
*Breastfeeding your children? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
*Never having children? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
*Going through menopause late in life, after age 55? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
*Having had breast cancer before? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
*Drinking more than two caffeinated beverages a day? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
*Being on hormone replacement therapy (HRT) after menopause? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
*Having your first child later in life, say after age 35? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
*Gaining 20 or more pounds after age 18? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Stages of Change. *These may seem similar to other questions that you have already answered, but they are a little different. I want you to think about what you yourself think or would be likely to do as I ask you these questions.*

{INTER: Read all answers in the set and fill in the circle of the one answer that R. thinks comes closest to what she believes or would be likely to do.}

{INTER: Show R. card #3.}

44. If I get breast cancer:

- ☐ God alone would cure it without help from doctors.
- ☐ God might work through doctors to cure it.
- ☐ God would work through doctors to cure it.
- ☐ Doctors would cure it with help from God.
- ☐ Doctors alone would cure it.

45. If I had surgery for breast cancer:

- ☐ Air getting to the cancer would make it spread faster.
- ☐ Air getting to the cancer might make it spread faster.
- ☐ Air getting to the cancer would probably not make it spread faster.
- ☐ Air getting to the cancer would not cause it to spread faster.

46. If I get breast cancer:

- ☐ I would not tell the man in my life about it.
- ☐ I am not sure if I would tell the man in my life about it.
- ☐ I would most likely tell the man in my life about it.
- ☐ I would definitely tell the man in my life about it.

47. Some women think that mammograms help to find breast cancer, while other women do not. What is your opinion about mammograms? Do you think that:

- ☐ Mammograms do not help in finding breast cancer.
- ☐ Mammograms might help in finding breast cancer.
- ☐ If I were concerned about breast cancer, I would get a mammogram.
- ☐ I would definitely get a mammogram every year after age 50.

48. If I found a lump or knot in my breast that did not bother me, I would:

- ☐ Leave it alone and do nothing.
- ☐ I might or might not go to a doctor.
- ☐ I would probably go to a doctor.
- ☐ I would go to the doctor immediately.

49. If I had surgery for breast cancer:

- ☐ Cutting on the cancer would make it spread faster.
- ☐ Cutting on the cancer might make it spread faster.
- ☐ Cutting on the cancer would probably not make it spread faster.
- ☐ Cutting on the cancer would not cause it to spread faster.



50. Have you ever known someone personally who had breast cancer?

☐ Yes

☐ No (**SKIP to 51**)

☐ (S.C. Not sure)

IF YES, what do you most remember about that person and her experiences?

{INTER: Record R's responses exactly.}

51. If you had a serious health problem, what one person, other than your doctor or God, would you turn to first for advice?

{INTER: Be sure to record the relationship to the person in the box i.e. sister, mother, husband, male friend. Be as specific as possible.}

Name: _____

Relationship

[illegible]

ID# _____

52. *Now I would like to ask you if you agree or disagree with some statements about relationships between women and men and breast cancer. There are no right or wrong answers. We are interested in your opinions about these statements that others have made. Please answer agree or disagree as I read each statement.*

	<u>Agree</u>	<u>Disagree</u>	<u>(S.C. Not sure)</u>
a. Most men would want to know if the woman in their lives developed breast cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Dealing with breast cancer is a woman's problem and the man in her life doesn't need to be concerned with it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Men are not as good as women at coping with serious illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. A man would probably leave a woman if he knew that she had to have her breast removed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. A woman is more likely to get support from her female friends or relatives when she is seriously ill than from the man in her life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. If a woman has breast cancer, she should tell the man in her life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Women who have surgery for breast cancer are no longer attractive to men.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. A man should help the woman in his life with her health problems.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. A man would probably not stay with a woman if he knew that she had breast cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

BELIEFS ABOUT CANCER.

53. *These next items are some of the things different women have told us they believe about cancer. We are interested in your opinions. Please tell us if you strongly agree, agree somewhat, disagree somewhat or strongly disagree with the following statements. Remember, there are no right or wrong answers- we just want your opinion. {INTER: hand R. Card #4.}*

	<u>SA</u>	<u>AS</u>	<u>(S.C.) (Not Sure)</u>	<u>DS</u>	<u>SD</u>
If a cancer is cut open in surgery, it will not grow faster.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Negative feelings can cause cancer.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If a person has cancer, there is no sense trying to do anything about it.- - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People who take good care of themselves usually don't get cancer.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A person with high blood is more likely to get cancer than a person with normal blood.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vaccinations weaken the immune system which can lead to cancer.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Luck plays a big part in determining who gets cancer.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is better to die whole than to let a doctor cut on your body.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Chemotherapy and radiation work better than alternative therapies to treat cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If air gets to a cancer during surgery, the cancer will grow faster.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cancer is <u>not</u> caused by dirty blood.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doctors and health professionals are the ones I would trust most to decide how to treat cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Antibiotics weaken the immune system which can lead to cancer.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone can give you cancer by putting a root on you.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

(QUESTION 53 CONTINUED)

	<u>SA</u>	<u>AS</u>	<u>(S.C.)</u> <u>(Not Sure)</u>	<u>DS</u>	<u>SD</u>
People get cancer when they are tired and their resistance is down.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Visualizing your body attacking cancer cells will <u>not</u> help to cure the disease.- -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Air getting to a cancer during surgery will <u>not</u> make it spread.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If you keep thinking you have cancer, you will probably get it.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Herbal remedies are more effective than medicines against cancer.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doctors experiment with people by cutting on their cancers.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with thin blood are more likely to get cancer.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nothing works to cure cancer so that it never comes back.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Positive feelings can help cure cancer.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
No matter what I do, if I am going to get cancer, I will get it.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If air gets in the place where the doctor cuts, then the cancer will kill you.- - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

INFORMATION ABOUT BREAST CANCER.

I want to ask you a few questions about any information you may have heard or seen about breast cancer within the past year. Please tell me yes or no for each of the following:

54. Within the past year, have you:

	<u>Yes</u>	<u>No</u>	<u>(S.C.) (Not Sure)</u>
Seen a television program or commercial about breast cancer? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Read about breast cancer in a magazine? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Heard a radio program or commercial about breast cancer? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Read about breast cancer in the newspaper? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Been to a <u>church</u> program on breast cancer or mammography? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Been to a program at a <u>club or civic group</u> on breast cancer or mammography? - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Been to a program on breast cancer or mammography <u>at work</u> ? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seen a pamphlet about breast cancer or mammography? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seen a video about breast cancer or mammography? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Participated in any local American Cancer Society activities like Relay for Life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Picked up information about breast cancer at a health fair? - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

58. During difficult times, do you rely on your religion:

☐ A great deal ☐ Somewhat ☐ Not very much ☐ Not at all

59. *For the next question, please tell me if you agree or disagree with each statement.*

If you were told that you had breast cancer, would you believe that:

	<u>Agree</u>	<u>(S.C. undecided)</u>	<u>Disagree</u>
God would work through the doctors and nurses to cure your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You would trust more in God to cure your cancer than medical treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You would refuse medical treatment and trust only in God to cure your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Only a religious miracle could cure your cancer, not medical treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your cancer would be because you had sinned against God.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It would be your responsibility to pray every day that God would cure your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The strength of your own faith in God would determine if your cancer was cured.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your prayer alone would do nothing to cure your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You would want your church members to come to the hospital to pray with you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your church members praying in church would help to cure your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There would be a special ceremony for you in your church to cure your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You would not tell anyone in your church about your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You would not ask people in church to pray for you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

DEMOGRAPHICS: *I just have a few final questions to ask you about your background.*

60. What is your ethnic group or race? Would you say it is:

☐ African-American ☐ Asian ☐ Hispanic ☐ Native American (American Indian) ☐ White ☐ Mixed ☐ Other

61. What was your age on your last birthday and what is your date of birth?

Age

--	--

DOB

		/			/		
--	--	---	--	--	---	--	--

62. How much schooling have you completed?

- | | |
|--|--|
| <input type="radio"/> Did not go to school | <input type="radio"/> High school degree/GED |
| <input type="radio"/> Less than 4th grade | <input type="radio"/> Some education after high school |
| <input type="radio"/> 4th-8th grade | <input type="radio"/> College degree |
| <input type="radio"/> Some high school | <input type="radio"/> Graduate degree |

63. Are you presently enrolled in school?

- ☐ Yes ☐ No, out temporarily ☐ No

64. Are you: ☐ Single, never married ☐ Married? ☐ Separated? ☐ Divorced? ☐ Widowed?

If currently married, for how many years?

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{INTER: Fill in all that apply.}

65. Who lives with you now?
- ☐ No one, lives alone
 ☐ Sister(s)
- ☐ Husband/ male partner
 ☐ Brother(s)
- ☐ Female partner
 ☐ Son(s)
- ☐ Mother/stepmother
 ☐ Daughter(s)
- ☐ Father/stepfather
 ☐ Other(s)

66. Including yourself, how many people live in your household?

--	--

67. How many years have you lived in this community?

--	--

68. Have you ever lived anywhere other than eastern NC?

☐ Yes ☐ No

If Yes, where did you live the longest?

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

(City, Town)

--	--

(State)

For how many years?

--	--

69. Do you have a telephone?

☐ Yes ☐ No

If Yes, what is the number?

(

--	--	--

)

--	--	--

 -

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If No, is there a number where you can be reached?

(

--	--	--

)

--	--	--

 -

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ID# _____

DEMOGRAPHICS--EMPLOYMENT/INSURANCE STATUS: *I just have a few more questions to ask you. These are about your employment status and the resources you have available to pay for medical treatments. This information will help us know whether some people have trouble getting the health care they need.*

70. At this time are you:
- ☐ working for pay full time [SKIP to 72]
 - ☐ working for pay part-time [SKIP to 72]
 - ☐ self-employed [SKIP to 72]
 - ☐ not working for pay

71. Are you:
- ☐ retired from paid employment
 - ☐ laid off from a job temporarily
 - ☐ unemployed with disability
 - ☐ unemployed but don't have disability
 - ☐ a student
 - ☐ or have you ALWAYS been a homemaker and not worked for pay [SKIP to 73]

72. What is/was your job called?

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

HEALTH INSURANCE, OTHER BENEFITS

73. What kind of health insurance do you have? Is it:

[INTER: Hand R. card #5. If two types of insurance are mentioned, fill in both. Fill in all that apply.]

- ☐ Insurance through a private company like Blue Cross
- ☐ Medicare
- ☐ The VA or CHAMPUS
- ☐ Medicaid
- ☐ An HMO or managed care plan
- ☐ Don't know **[SKIP to 75]**
- ☐ Don't have any type of health insurance **[SKIP to 75]**

74. Did you have health insurance last year for:

- ☐ the whole year ☐ or part of the year ☐ (S.C. not sure)

75. At any time in the last year did you not go to the doctor or get medical care because you could not afford it?

- ☐ Yes ☐ No

FAMILY INCOME

76. Please look at this card. **{INTER: Hand R. Card #6.}** Tell me the number that comes closest to your total family income last year. I mean the total for all the people who lived in your home last year, before taxes. Be sure to count all types of money, from wages and salaries of all family members, Social Security, retirement or unemployment benefits, help from relatives and so on. Let me remind you that this information, like all your answers, will be kept completely confidential.

- ☐ 1-under \$5,000
- ☐ 2-between \$5,000 and 7,999
- ☐ 3-between \$8,000 and 11,999
- ☐ 4-between \$12,000 and 15,999
- ☐ 5-between \$16,000 and 24,999
- ☐ 6-between \$25,000 and 49,999
- ☐ 7-over \$50,000
- ☐ 8-(S.C. don't know)
- ☐ 9-(S.C. refused to answer)

77. How many people did this income support last year? # of people supported

--	--

HEALTH STATISTICS.

79. What is your height?

ft.

inches

80. What is your weight?

lbs.

CONCLUSION

Thank you so much for taking time to talk with me today. Those are all the questions I have for you. Is there anything you would like to ask me about this project?

{INTER: RECOMMEND STRONGLY THAT THE R. SEE A DOCTOR/NURSE IF SHE HAS A LUMP OR KNOT NOW IN HER BREAST. (#27)}

Are there any comments you would like to add?

<hr/> <hr/> <hr/>

TO THE INTERVIEWER:

Please be sure to check over the entire interview to make sure that all questions are answered and that the answers are clearly marked. Also be sure that there are no stray marks on the interview anywhere and that you have filled in the ID# at the bottom of each page.

ID# _____